CAPP ACPP
Canadian Association of Psoriasis Patients
Association canadienne des patients atteints de psoriasis

Canadian Association of Psoriasis Patients
Annual Report
2016-17

The Canadian Association of Psoriasis Patients (CAPP) completed a productive year as we developed new partnerships, worked to solidify relationships with current stakeholders and worked on innovative and interesting projects, all aimed to help us achieve our mission which is *"to be a resource and advocate for psoriatic patients and their families to improve patient care and quality of life."*

Studentships in Psoriatic Disease Research

For the first time, CAPP offered a new summer studentship program for medical students with an interest in psoriatic disease. The goal of this program is to create a new generation of researchers and encouraging medical students to enter into the field of dermatology. Working in partnership with the Canadian Institutes of Health Research – Institute of Musculoskeletal Health and Arthritis, Janssen and Leo Pharma, we were able to fund six students for the summer of 2016.

The inaugural group of students has been very successful in terms of publications and presentations. Two presented posters at the Canadian Dermatology Association conference, one presented a poster at the American Academy of Dermatology. Another student published his results in the prestigious Journal of Investigative Dermatology.

More importantly, three of the six students continue to be ambassadors for the Canadian Association of Psoriasis Patients (CAPP.) They write articles for the newsletter, work on special projects and/or represent CAPP at various events.

IPSOS Psoriasis Patient Survey

The goal of this survey was to increase actual patient data for patients living with psoriatic diseases in Canada, as little existed prior to this project. In particular, the survey was designed to help us understand psoriasis severity and impact on life, awareness and usage of treatment options, treatment satisfaction and performance and awareness of psoriasis resources.


Psoriasis Patients
Quality of life, Treatments, and Resources
September 2016

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With 343 participants completing the survey, the results indicated that they were satisfied with their current treatment, particularly those on a biologic. Two in five patients often need to take time off from work as a result of their psoriasis and diabetes and hypertension are the most common comorbidities among psoriasis patients. The results have been shared extensively including a presentation at the Canadian Dermatology Association conference.

World Psoriasis Day 2016

Building on the success of the pediatric animation video completed in June of 2016, CAPP launched a children's art contest to mark World Psoriasis Day 2016. The objective of this project was to encourage students from across the country view the video and then submit a piece of work which represents what they believe it must be like to live with psoriasis. We were thrilled to receive more than 67 entries, 39 that met the eligibility requirements, and we announced the winners on World Psoriasis Day. A selection of the entries were used to create a desk top calendar that was distributed to our stakeholders as a small token of thanks for supporting CAPP activities.

Partnerships

CAPP was invited to participate in the Beer Store Charity Scramble. This was an excellent opportunity to raise awareness of the organization with a different audience and benefit from the proceeds of this event. Thank you to the Beer Store for including us in 2016!

This year marked a positive evolution in the relationship with the Canadian Skin Patient Alliance (CSPA). Representatives of both the CSPA and CAPP came together to re-align the relationship from a subsidiary in nature to a true partnership. A funding agreement was introduced to outline human resource and financial responsibilities, communications strategies and potential areas of collaboration.

CSPA Canadian Skin Patient Alliance

CAPP partnered with the Happiness Research Institute, in partnership with LEO Innovation Lab to promote the PsoHappy survey in Canada. The objective of this survey is to understand the link to living with psoriasis and elevated levels of stress and feelings of isolation, and in some cases, depression in Canada. Results are expected in the fall of 2017.

CAPP was thrilled to be the recipient of an in-kind donation from Janssen Canada of the "Living Well with Psoriasis" Facebook page. This asset came to us with a log of past posts as well as over 14,000 followers. Thank you Janssen!

CAPP is proud to represent Canada at the International Federation of Psoriasis Associations (IFPA) and participate regularly in their webinars and face-to-face meetings. This year their Annual Meeting was held in Brussels and focused on training for World Psoriasis Day, organizational development as well as an advocacy workshop on psoriasis in the non-communicable disease (NCD) context.

Advocacy Efforts

CAPP continues to advocate for equal access to best care and treatment for patients living with psoriatic diseases in Canada. We believe that a decision to have access to treatments should not depend on your postal code. As such, we developed patient submissions at the provincial level (BC and Quebec) to support two new treatments. We updated our position statement on biosimilars and advocated against cuts to dermatology training for medical students at UBC. And, we met with representatives at the Public Health Agency of Canada to advocate for more awareness of the challenges of living with psoriatic disease at the Federal level.

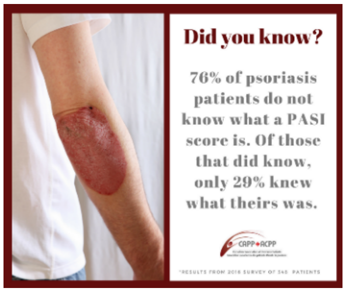
Raising Education and Awareness

CAPP worked on a number of activities to help raise awareness of the disease itself as well as the role of the organization:

- Two of the CAPP Board members, Eva Borkenhagen and Brooks Harvey, hosted a booth at the Tsu'tina Health Fair in Calgary Alberta.
- Participating as patient representatives, two CAPP Board members, Morris Manolson and Shawn Swayze, participated in a social media Focus Group for Leo Pharma.
- Morris Manolson and our Executive Director, Kathryn Andrews-Clay, participated in a Patient Reported Outcomes meeting hosted by Janssen Canada to prepare for the introduction of a new biologic in Canada.
- The CAPP e-newsletter is now available four times per year and is translated into French. We also began promoting on social media to increase readership and subscriptions

Social Media

This year, CAPP took a much more aggressive approach to social media in an effort to raise our reach and engagement with Canadians. We were fortunate to be gifted the Living Well with Psoriasis Facebook page from Janssen which brought with it a community of over 14,000.



We started a Facebook Campaign called "Pso Did you know…" that carried over to the next fiscal year using data from the two different surveys to highlight the results of the surveys.

We increased our Facebook following by 120% and our twitter following by 17%. Our social media activities had an overall reach of almost 1.5 million Canadians.

Our website continues to receive traffic with over 12K users coming to our site in 2016-2017. 81% of our users are first time visitors, and the home page and medication access tool are the top visited pages.

Volunteers are the backbone of the organization!

A new program was introduced in 2017 called the “Volunteer Ambassador program.” Volunteers are being recruited to help with special events and activities in their region on behalf of CAPP. Being such a small organization, we depend on these ambassadors to help us with activities across the country. The first Volunteer Ambassador started in the spring of 2017 and helped facilitate a focus group of patients.

CAPP would like to thank the many people who contribute to the organization including the, the members of the Board, the CAPP-funded students who have worked on other projects for us, the dermatologists who guide us and the patients who keep us grounded to our mission and vision.

With sincere appreciation to our Sponsors!

CAPP is grateful to the support we received this fiscal year from our many sponsors. Working collaboratively, we have been able to accomplish so much. Our funders for 2016-17 were: AbbVie, The Beer Store Charity Scramble, Celgene, Eli Lilly, Janssen and Novartis. We also thank CIHR-IMHA for their ongoing support of our studentship program.